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Montana Perinatal Program

WHEN YOUR BABY HAS DIED . . .

PRACTICAL SUGGESTIONS AND EMOTIONAL SUPPORT FOR GRIEVING PARENTS

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QUOTATIONS FROM PARENTS

"At first, it felt like I died with that baby—there was nothing left, no reason to go on or so it seemed—this was what happened to other people, not us, not our baby"

"It can help to know you're not alone—you're not the only one whose baby has died."

"In the beginning, I felt like such a failure and the sense of loss was extremely painful—talking about what it felt like with friends brought relief."

"At the time, it seemed like the end of the world—it wasn't It does get better and time helps."

This booklet has been adapted, revised and expanded from a handout called "Fetal and Newborn Loss Support Group," by Mary Krugman and Karen Harvey, Rose Medical Center, Denver, Colorado. We acknowledge their contribution with appreciation and gratitude.

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INTRODUCTION

This little booklet has been written to help parents who have just lost a baby or young child It has been designed to offer you practical advice and reassurance at one of the most difficult times of your life

The booklet has been divided into two sections to help you cope with problems which face you now, and later with problems which may develop in the weeks and months ahead Of course, not all parents face each of these problems after the death of their child. But the experiences of other parents who have lost a child to death, including the author's, show that some problems are common occurrences as we try to deal with the shock, grief, and mourning brought on by the death of a child. You can learn from our mistakes Sometimes, it has been shown, if we are more prepared for events which MAY happen, we can also be prepared for how to handle them

Two things are important for you to know now

1 YOU ARE NOT ALONE First of all, you are not alone because many other families have lost a child to death. Their experiences can help you now. Other parents have said that just knowing you are not the only one whose baby has died helps a little in coping with grief Secondly, you are not alone because there are lots of people who want to help you now, especially your families, the hospital staff and your doctor Sometimes, perhaps, you may have to help them to help you, because not even professional people always know the best way to help That's another reason this booklet has been written — so you will know how to help them to help you Your family, your hospital staff, your doctor — they are the people who can help you the most

2 YOU WILL SURVIVE The bitter grief you feel now does lessen even though it may feel now as if it never could Time helps time heals You may need to hang on to that thought — which other parents have expressed "TIME DOES HELP" Live one day at a time Survive that day In the days and weeks and perhaps months ahead, remember You will survive!

THE FIRST FEW DAYS

During the next few days you will have to make many decisions which you not only have never made before, but which you probably have never even thought about before Decision making is never very easy, but when you are sad, confused, and in shock, it is very difficult indeed, if not almost impossible Our brief outline is designed to simplify and help you make those decisions In addition, you should feel free to ask as many questions as you need answers to — of as many people as necessary — to get answers which will help you If someone — a nurse, your doctor, an office worker — gives you a short and unsatisfactory answer, ask someone else who can give you a better answer If it is easier for you, write your questions down — or ask a nurse or a social worker to write them down for you, and ask the person helping you to get answers you can understand Remember that other people are saddened, confused or frightened by death. If they can't or won't help you, it may be that they have never learned to handle the thought of death, especially the death of a child. Ignore those people, they don't mean to hurt you But don't let them stop you from asking questions and getting answers. Find someone who will help you. Most people will try to help you the best they can

Don't let other people make decisions for you, even close family members who are trying to protect you from more grief and strain Take their advice, or ours, if you wish to, but DO WHAT YOU WANT TO DO. Often parents have said that they later regretted making that "sensible" decision someone else insisted on instead of following their own ideas So don't let anyone push you into doing things one way when you would rather do them another way.

Unfortunately, many decisions which need to be made around the death of your baby will have to be made quickly, at

a time when you really can t think clearly at all It helps if you take one decision at a time, talk it over with whoever can give you the best answers to your questions and then decide for yourselves what you want to do Take as much time as you need with each decision and then go on to the next one If you find you can t live with one of your decisions and want to change your mind, it's your right to do so if the prior decision is not already irreversible

IMMEDIATE DECISIONS

Seeing and Holding Your Baby You probably will be asked almost immediately if you want to see and hold your baby You may want to say "Yes now " or "Yes but a little later or "No not at all " You may even want to say "Give me some time to decide " Ask how long you have to decide about seeing your baby Don't be rushed into a decision more than necessary The hospital staff should go by your decision and should not pressure you to see or not to see your child They should give you enough time (at least a day, if necessary) to make this decision, and as much time as you want with your baby if you decide to see him or her Most professionals who have helped parents through the ordeal of the death of their infant believe that it helps the parents with their grief later to see and hold their baby now after he or she has died It gives you a chance to get to know your baby (if you have not seen him or her before), to rock or cuddle your baby, and to say "good-by" to your baby It will not be easy for you, and you may want to scream or cry, or want to throw things That s okay People will understand

If you are not used to seeing death, it may be doubly difficult for you to see the death of your own child You may be frightened, or feel sick Don't feel ashamed or guilty — your feelings are perfectly natural If you wait for a while to hold your baby, he or she may be pale and a little stiff This is a

natural result of death Seeing your baby a little later usually can be arranged in the hospital or in a funeral home.

You may want someone with you when you see your baby or you may want to be alone with him or her Your wishes should be respected If necessary you can ask the nurse or social worker (or funeral director) to leave the room so you can be alone **Spend as much or as little time seeing and holding your baby as you need to say good-by to him or her.**

Naming Your Baby If your baby is stillborn or dies as a result of a miscarriage you may be asked whether you wish to give the baby a name — so that the birth and or death certificate can be completed **You don't have to make a hasty decision**; usually you have a few days to decide

If you already have a name picked out you may want to go ahead and use it However, if it is a favorite family name which has been used for generations, you may wish to reconsider and give your child another favorite name The baby has been a part of your lives for many months now, and **you should do whatever feels right for you**. You may want to "try out the name for a day or two, to see if you feel it is the right name for your child

If you as parents disagree about the right name for your baby, talk it out with a nurse or a social worker, or with your family doctor or minister They may help you reach a compromise at a time when you don't have much reserve strength left for disagreements

If you don't want to name the baby, that's okay too You are the one who knows what feels right for your child

An Autopsy It is likely that someone will ask you about performing an autopsy **An autopsy is the examination of the body after death**. This involves the careful examination

of the internal organs and tissues for causes and or factors contributing to death Often this is done to help doctors try to find ways to prevent other babies from dying the same way in the future Sometimes it helps to reassure you that nothing could have been done to save the baby The person performing the autopsy is a pathologist

You may need to sign consent forms in order for an autopsy to be performed If you have questions or concerns about the autopsy, please take your time **Ask questions and get them answered to your satisfaction.** Complete results of an autopsy should be shared with you as soon as possible to help you better understand the problems of your baby and if necessary to assist you in planning future children Preliminary results are usually available much sooner If you are not told the preliminary results ask your doctor, the coroner or pathologist at the hospital for them Ask when the final autopsy report will be completed **Make an appointment — for several weeks or months from now if necessary — to hear the final report** You have a right to know the full autopsy report, if you wish

An autopsy usually does not disfigure your child s body It is often done with such skill that it is scarcely noticeable later The question of an autopsy is such a personal issue that deciding to do it depends upon the questions that both the parents and the doctor may have concerning the death If the cause of death is obvious and you feel no reason to question it you may choose to forego the procedure However you may find it necessary **for your own peace of mind** to have an autopsy done

The Funeral and Burial or Cremation A funeral for your baby can provide an opportunity to receive support from your family and friends The period of visitation and the funeral give others an opportunity to visit with you in a socially accepted way so they may express their love and concern for

you It will also give you a chance to express your grief with people who are close to you The warmth you feel at this time will help you feel close to others during this very lonely period In the days following the funeral, you will recall the support you received

If you are planning a burial or funeral for your baby, hospital personnel will need to know the name and location of the funeral director whom you have selected. Some funeral homes offer low cost infant burial Have someone else (a family member perhaps, or someone from the hospital staff) call around before making the decision as to which funeral home to use, unless you know one that you especially wish to use — one that perhaps your family has used before The hospital will contact the funeral director to let him know when he can come to the hospital for the baby A local funeral director must also be contacted to arrange for an out of-state burial If the baby died in an out-of-state hospital your local funeral director can make arrangements for you to bring the baby home

If you do not wish a burial the funeral director can have the body cremated after a funeral, and he will either give you the ashes or take care of them as you wish You also may have cremation without a funeral

If you prefer not to have a burial or a funeral, some hospitals provide the option of a hospital cremation This requires your signed consent Ashes are not always available to the family as they are in a private cremation You will not be able to have a funeral for your baby You may, of course, always have a memorial service instead

Another option sometimes available to you is the donation of the body to a medical school for research purposes This too, requires your signed consent Ask someone on the hospital staff how to make the necessary arrangements

If you choose hospital cremation or donation of the body to a medical school, you can still have a meaningful service for your baby You may choose a small informal church memorium Some parents have gathered a few people who are close to them in the mother's hospital room, in their living room or backyard, or some other place that is special to them Parents have written and conducted their own service Parents who have formal or informal services usually agree that this was an important step in the grieving process for them — a way they could acknowledge that this baby, even though so young, was loved even before birth and was a person who meant a lot in their lives If you do not feel the need for any type of service, you should not feel that you have to have one. The decision is entirely up to you and your family — whatever feels best for you

Sometimes after a child has died, the mother is confined to the hospital In the interest of her health and well-being some family members — or even her husband — may attempt to shield her by not informing her of the plans and arrangements being made for the funeral As Roy and Jean Nichols, authors of "Funerals A Time for Grief and Growth," say "In death and grief we do not need as much protection from painful experiences as we need the boldness to face them." As much as possible, the mother should be included in the planning. If she wishes, plans should be made so she can attend the final rites The services can even be delayed for a few days

Other children in the family also should be encouraged to participate in the funeral or memorial service, since this is an important family ritual If the ritual is explained beforehand, the child will be better prepared to attend the ceremony If your younger children do attend, ask another family member or close friend to look after them In that way, you do not have to be distracted if they need attention or have to leave the service, and you know they will be in good hands An older child may be given some role such as greeting

mourners at the funeral parlor, answering the door or telephone if people call at home, or passing food if a wake is held. In considering your other children when making funeral arrangements, be reassured that seeing adults cry will not be harmful to a child. Indeed, it may be comforting to know that adults have the same feelings the child does. If, after preparing your other child (or children) by explaining the funeral ritual, a child does not wish to attend, it is probably best not to insist. Be sure to reassure him (or her) that you love him very much, and that you think it is all right if he wants to stay home with a family member or friend.

It may seem easier or kinder to send your other child (or children) away to visit relatives or friends during the first difficult days after the death of your baby when you are so upset yourselves. However, children can always sense when something is seriously wrong and sending them away may give them a feeling of being abandoned and left out. When they are told about the baby's death, they will be grieving, too. They need the comfort of familiar surroundings and loving family members at this time. Even if it is difficult to talk with them and take care of them, they should be kept close to you, and the baby's death explained at the level of their understanding to the best of your ability. Perhaps you could ask a family member or friend to help you with their care in the first few days until you feel better able to cope with routine tasks again.

THE NEXT FEW WEEKS AND MONTHS

GRIEF

The grief you feel for your child who has died brings pain but perhaps the hurt can be lessened by understanding what is taking place and how other parents have reacted The nature of grief itself is often difficult to understand but grief does seem to follow a pattern. The distinct phases of this pattern are shock and disbelief acute mourning and suffering, and recovery These steps can overlap and you might find yourself sliding from suffering back to shock or feeling periods of intense suffering in the recovery period You also will move through these phases at your own pace there is not a set timetable Complete resolution of grief is obtained when you can remember comfortably and realistically both the anticipated or actual pleasure and the disappointment surrounding your baby's birth and death

Shock may begin with the knowledge that your infant is abnormal or seriously ill, or that your infant has died Instinctively you may think to yourself or say out loud phrases like "No, it can't be true!" or "Not my baby!" You will have difficulty concentrating, taking care of details and trying to make decisions You may find that it is hard to think clearly Your feelings may range from guilt and anxiety to anger depression and hopelessness The distress caused by the intensity of your feelings will be severe There are times when many people in this situation feel that they are losing their minds

In addition to these reactions of your mind your body will also respond in ways that are uncomfortable and foreign to you You may burst into tears — more often than you might expect — for what seems to others to be no good

reason at all Your appetite may disappear You may be completely exhausted and yet find sleep restless and unrefreshing On the other hand, you may have an increased desire to sleep You may feel faint and generally numb all over Some people feel cold or nauseated or have sensations of tightness or pain in their abdomen or chest A frequent reaction expressed by parents is a strong yearning for physical contact with their baby — the feeling that "My arms ache to hold my baby" This is referred to as the empty arm syndrome Sometimes a mother will say she can feel her baby kicking or hear him crying That's a normal feeling — uncomfortable and distressing, but not "crazy"

During this period of turmoil, expressing your true feelings is healthy and the emotional release will ease what is to come However, friends and relatives may not be willing to accept and forgive unpredictable or unusual behavior for very long They may be tolerant until the funeral is over, for a week or perhaps a month Then you frequently may be encouraged to "Pull yourself together" or "Get on with your life" Friends and relatives are not intentionally unkind People who have not suffered grief may be unaware of the severity of a grief reaction and the amount of time needed for healing to occur It is all right to let them know in a matter-of-fact way how you still feel about the death of your child, but don't expect them to understand If they cannot understand and agree with you, they may withdraw from you This will hurt, and you will have to deal with these feelings later For now, try to let it go for your own peace of mind Remind yourself that grief is difficult to understand if you have not experienced it

Mourning, the second phase of grief, is the long, slow adjustment of living without someone you anticipated and loved even before birth Frequently family and friends have drifted back to their own lives Husbands and wives may be at different stages of grief and may deal differently with

grief and their ability to talk about it They may expect their partner to react as they are reacting and resent the difference You may feel very lonely and isolated even from your partner The temptation to withdraw completely beckons Physically you may feel as though you are moving in slow motion and even the most routine daily tasks seem monumental You still may cry easily You may notice that you are frequently sighing or swallowing for no apparent reason and that you still have trouble sleeping

As you go back and forth between shock and suffering you may feel anger against the doctor the nurses and the hospital for not saving your baby You may also be angry at God or at life for doing this to you You should try to identify and acknowledge your feelings without being ashamed of them Sometimes anger is turned inward and depression may result Many times during depression you may find you lack interest in events of the outside world and that activities you usually enjoyed are dull and meaningless Along with this may be a loss of interest in your appearance and personal hygiene

Recovery is the third stage of grief Like shock and mourning it does not happen quickly There will be guideposts along the way in the months ahead Your thoughts will become active and look toward the future You will look at a variety of approaches some will be sensible and others may be wildly impractical or born of wishful thinking You should be patient with yourself and take time in making major decisions As you continue to progress you will find that your actions are no longer just "going through the paces" because you are "supposed to act in a certain way" Instead, your actions will be your choice You will be efficient and needed at work be able to give to friends and again be capable of enjoying nights out, parties picnics, and vacations

Be prepared to backslide. Getting through the first few weeks may seem impossible and grief will seem to envelope you Slowly you may find it becomes easier to participate in life and go out occasionally For some this comes with much difficulty We urge you to try however, because experience has shown that the longer you stay isolated and withdrawn, the harder it is to go out Eventually though, it does start to seem easier At some point, perhaps four, five, six or even nine or ten months later, the same lost, sad feelings may return Be prepared to backslide Be prepared for people to not understand your depression or sadness

During recovery there may be certain events that may cause you to lapse into suffering : facing the death of another loved one, your baby's birthdate, or even the arrival of the month in which your infant was born This is temporary and to be expected and recovery is still progressing You will not forget the important details of your baby's birth and death They are a permanent part of your life experience However, as recovery becomes complete, you will be able to live and hope in the present and for the future

REACTIONS OF RELATIVES AND FRIENDS TO YOUR BABY'S DEATH

In the beginning, your friends and relatives will be touched by the loss of your baby and will want to extend their sympathy and try to comfort you. This is not easy to do Some people are able to sit with you, listen to you, and possibly share your tears Some friends — even close ones — may avoid you after your baby's death or if they do see you may chat about trivial things Other people may seem uncomfortable around you and say things that seem insensitive or even cruel

Occasionally, you may find a relative or friend who will blame you for your baby's death It may be their angry

response to an unexpected death, and they are lashing out at you in frustration and despair This may hurt deeply and add to your own dispair Talk with your doctor and tell them his explanation of your baby's death If they persist, ask them to leave you alone for a while, until you all can talk about the death more reasonably Then turn for comfort to your partner or a close friend or your minister or priest Don't accept the blame; fight it, with your doctor's help, if necessary

It may be difficult to understand friends' negative reactions, particularly when your own feelings of grief are very intense Most people do not think about death except when circumstances force them They would prefer to avoid the issue as much as possible When one faces the death of another person, one must think about one's death as well These thoughts are often unpleasant and frightening When people are struggling with these feelings within themselves it is difficult for them to respond in a helpful way to your loss Usually it is their own discomfort with death that leads them to make thoughtless or insensitive remarks They are doing their best to comfort you, and certainly are not trying to add to your pain. They may not say the right things, but their intentions are good It is sometimes difficult, however to keep calm when you hear some statements such as

"It was a blessing the baby died "
"Now you have a little angel in heaven "
"It's a shame you didn t have a miscarriage " OR "It s a good thing you did, that means the baby would have been deformed " (Not necessarily true)
"You're young, you can always have another baby "
"Be brave Don't cry "
"It's not the end of the world "
"Everything will be all right "

It is usually best if you can respond to such statements in ways that will not add to an awkward situation and thereby increase your own distress Often you can respond to the

other person's desire to be comforting, rather than to their exact words You can simply respond with your own feelings, such as

"Thank you for thinking of us It helps to know that "
"We loved our baby, and we're sorry that she/he died "

Often there may not be a need to put your feelings into words at all Simply reaching out to clasp the other person's hand may be more eloquent than anything you can say Later you can share your feelings of anger or annoyance with your spouse or an understanding friend

Occasionally someone will say something that will particularly anger you and make you want to respond directly It is best not to get into an argument or to launch into a personal attack on that person because you will probably feel worse after it is over A comment that is a clear and direct statement of your own feelings may work better

"I don't agree with you "
"That isn't how I feel about it "
"It doesn't help me to think about my baby's death in that way "

Although you may have caring and helpful people around you at the time of your baby's death, you may find that as the weeks and months go by, people may drift away and not reach out to you as much as they did at first As they become involved again with their own lives, they may not realize that you still need their support The best way to get what you want from them is to ask for it. Most people will be glad to take the time to be with you if you let them know that you need them

You also may find that you can almost "teach" people to be more comfortable talking about your baby's death People will probably take their cue in the conversation from you If

you as parents can deal with the reality of your baby's death, your friends and relatives may begin to be less frightened by it as well

As time passes, you will learn what to expect from people and will develop ways of responding that work best for you In this way, you will not have to relive your grief each time someone expresses their sympathy about your baby's death This will help you resume your life despite your loss

ESPECIALLY FOR FATHERS

An important thing to remember is that some fathers may not go through as intense a grieving process as the mother. Part of this is due to the fact that a mother feels closer to the baby during the time of pregnancy while the father is more likely to develop this feeling during and after the birth of the infant While he shares with his wife the feelings of shock, loss and anger, these feelings may ease up sooner for him than for her, especially if the death is a result of a stillbirth or miscarriage This is only natural, since he had less time to get to know the baby well

There are several problems that can arise from this As time passes, the father may expect the mother to "recover" faster than she does On the other hand the mother may be feeling that the father isn't grieving as much as she is If both parents realize this difference, they will understand why they grieve differently, and respect each other s grief An important thing to remember is that while "time heals," there is no standard span of time to expect the healing of grief.

Some fathers try not to show their emotions in front of their partner because they believe they must be a "tower of strength" for her Being a source of strength though doesn't mean not crying or expressing sorrow It means sharing

sorrow, listening to feelings with sympathy and expressing your own feelings, whatever they are, in return If the father doesn't show his emotions, it may give the mother the feeling that she is grieving alone and that her partner "doesn't care " Each of you has the right to grieve in your own way and at your own pace. If you do not always share the same feelings, you must give each other the freedom to express those feelings in an atmosphere of understanding and support

Don't try to be strong for your wife Grieve with her. Grieving can be more difficult for couples if they don't share the emotions of the grief process.

HELPING YOUR OTHER CHILDREN WITH GRIEF

Although your initial instinct may be to "protect" or "shelter" your children from the sadness of life, most professionals agree that one should be open and honest with children about death A simple statement about the baby having died as soon as possible after it happens may be difficult to say, but allowing your own sadness to show and sharing these feelings with your children can bring all of you closer together No matter how young your other children are they need to know about this tragedy

If your children are quite young, they may not know what death or "being dead," means They may not have seen anyone or anything that they thought of as "dead " Reminding them of dying flowers, a dead animal in the yard or road, the death of a favorite pet (theirs or someone else's) or another experience with death may help them to understand what dead means One can also remind them what living means — such as breathing, talking, walking, eating, etc , and tell them that dead means the absence of these signs of life Death should not be referred to as sleeping, since this may lead to sleep disturbances in the child Using terms such as

"lost" or "left" may cause confusion in the child's mind. Death should not be linked too strongly with illness, as this may lead to fear or panic if a minor illness develops in the child or another family member. The child may indeed need reassurance that he or she is well. The first illness of the child following the death of the baby may be especially stressful, and need repeated explanations and reassurances that the child won't die or be disabled as the baby was.

Children may ask about what will happen to the body of the infant. If there was a funeral or memorial service, it should be recalled. The necessity of burial or cremation may be stated simply.

Many children will want to know why the death occurred. Again, simple, honest statements about the physicial reasons will be helpful to your child. If the reasons are unclear, saying you don't know is all right. Explain why you don't know, however, so you don't leave the child with the feeling that he or she could die any minute. (You can, for example, explain that we don't know why an infant dies of Sudden Infant Death Syndrome, but that it usually occurs to babies between one month and twelve months, and never to older children.)

If you believe in an afterlife, share this belief with your children, but be cautious in telling children that "God took the baby to Heaven because He loved and/or needed the baby more than we did." This statement can cause resentment against God or a conflict in the child's mind about being less loved by God.

Another point which should be stressed is that no family member could have caused or prevented the death by any action, thought or wish. This is especially important if the pregnancy was unplanned or unwanted by any member of the family, or if the death was a Sudden Infant Death Syndrome, for which there is no good explanation at this time. Young

children believe that wishes are powerful and may believe that they or another family member caused this infant's death

The reaction of your child to death will depend to some extent on his or her age. A wide range of responses is normal, from constantly talking about the death to refusal to speak of it at all If constant talk about the baby disturbs you and seems too much for you to handle as you struggle with your own grief, perhaps you could ask someone else — a grandmother or grandfather or your minister or priest — to listen to your child part of the time If you possibly can, stop your reaction to cry out that you don't want to hear any more, because it is important to let a talking child go on talking That is how your child handles his or her grief for the death of the baby If your child refuses to talk at all, perhaps you could draw him or her out sometime when you are alone together, by asking leading questions which can't be answered by a "yes" or "no" If the child, usually an older child, walks away from you, let her (or him) go, but be sure she knows that you are willing to talk to her about the baby's death whenever she is ready.

Pre-schoolers will view death as temporary because the concept of "permanent" is too advanced for them Gently indicating that the baby will not come back is sufficient, although you may have to say it more than once, in several different ways When the child is older, he or she will begin to understand Pre-school and younger school age children may develop fears which grow out of fantasies about their own or their parent's death Because openly dealing with strong emotions is difficult for this age group, they may deal with them piecemeal — over a long time in their questions, dreams and play You should let them set the pace, listen lovingly to what they have to say and answer all questions simply and honestly Asking questions may draw out what they are feeling and thinking. Then you can correct misconceptions and offer reassurances

Pre-teens and teenagers will have a somewhat more adult view of death and will grieve much the way you do They understand the permanence of death but may need to deal with issues of why and of fault **Children of all ages will grieve and must be allowed to do so**, to relieve the feelings generated by the loss of a family member

Because of their stage of psychological development adolescent girls may have an especially difficult time dealing with the death of an infant They may feel a considerable amount of anxiety and/or anger about it

Showing younger children the cemetery and the burial plot may help them realize what has happened to the baby If the baby was cremated, you can explain that during cremation, the baby's body was warmed by a "light like the sun," and that the infant felt no pain in the process If the child wants to know where the body is now, you can say it was "returned to nature" as are all plants, animals, and humans when they die At this point, you may repeat your own beliefs about the existence of an afterlife

Months or years after the death of your infant children may need to recall the event and begin again to question you regarding their brother's or sister's death Any major event in a youngster's life is commonly relived in adolescence Later questioning and reliving of these issues is part of growth and development and should be viewed as normal

WHEN YOUR BABY DIES OF BIRTH DEFECTS

Each year thousands of babies are born afflicted with birth defects Often, if the birth defect is severe, the baby will not survive the birth process and will be stillborn or will die shortly after birth

As the parent of a baby stillborn as the result of

malformations you may truly feel overwhelmed Not only do you face the loss of your child you must make some sense of your child's condition You wonder "Why me?" "Was it my fault, in some way?", "What is wrong with me?"

It may be extremely difficult for you to discuss your child's death with friends and acquaintances On the other hand perhaps you choose to mention that your baby did die as the result of birth defects Your acquaintances may confide that they or some of their friends have had a similar experience Sharing feelings with someone who has experienced a similar loss may help you through your grieving.

You may feel more comfortable not discussing the cause of your baby's death with co-workers and acquaintances Sometimes you may feel pressured to answer questions to be polite But it's all right to quietly say something like "It is just too painful for me to discuss," which should make your feelings apparent without embarrassing your acquaintance

In addition to feelings of shame and embarrassment, you may struggle with feelings of overwhelming guilt Somehow you may feel responsible for your baby's malformation and death Even if your doctor has reassured you that you are not at fault, irrational thoughts may keep returning

A visit to a Genetic Counseling Birth Defects Clinic may be a valuable experience and could help dispel your feelings of guilt Researchers at such clinics are looking for the causes of birth defects In 80% of the cases there is nothing "wrong" with either parent Also except in rare instances (as with drug and alcohol abuse), the parents are NOT responsible for their child's defects You may feel very reassured knowing these researchers and doctors are experts with up-to-the minute information on the subject If your feelings of guilt return you may find it helpful to mentally replay your conversation with the genetic counselor If you wish to see a genetic counselor, ask your doctor or a nurse at the hospital

where the baby was born how to make an appointment In addition to possibly finding the cause of your baby s birth defect, the genetic counselor may help you immensely in planning for future pregnancies The counseling and advice may provide some peace of mind and help reduce your tension during these pregnancies

THINKING ABOUT ANOTHER PREGNANCY

Some time after the death of the baby you ll probably begin to wonder about getting pregnant again "Should I have another baby?" and or "How long should I wait? You may receive conflicting advice from your doctor, nurses, friends and relatives You may be told anything from Go ahead and get pregnant any time after three months " to Wait at least a year, preferably two " Someone may tell you "My sister waited so long that she never did get up the nerve to try again " or "My friend got pregnant too soon and had a miscarriage " It is hard to sort through this advice When, or whether, to get pregnant again is a personal decision only you can make together Perhaps making that decision will be easier with some thoughts and general guidelines based on the experiences of other bereaved parents and of professionals who work with them

The thought of another baby someday may be very comforting to you and may seem to help cushion the shock of the death of your child You may feel that the only way you can ever recover from this sad experience is to have a baby in your arms to love Your body, your home and your whole life is ready for a baby right now To have to wait at all seems too cruel The desire for a baby can be so strong you might want to call up adoption agencies immediately, get pregnant again as soon as possible or even have fantasies about an unwanted baby left in a basket on your doorstep

DO NOT make a hasty decision now, as you are struggling with your grief for the baby who died. Like other decisions discussed earlier, you should be patient with yourself and take time in making such a major decision. You will almost certainly find that other feelings about a new baby grow stronger as the days and weeks pass. You come to realize that the joy of another child will never "make up" for your sorrow over the death of this baby. You resent it when people say, "At least you can have other children" or "You can always have another baby." In the pamphlet, "The Subsequent Child," written for the National Sudden Infant Death Syndrome Foundation, Carolyn Szybist writes:

"When an infant dies, well-intentioned people generally try to persuade the parents that having another baby as soon as possible is the only answer to accepting that death. Rather strong attempts may sometimes be made to convince you that healing can only be accomplished this way. But "healing" is actually nothing more than incorporating an event into your life that enables you to live with it in an appropriate fashion. Doing that takes time. You cannot necessarily speed up the process of healing by having or not having another baby."

If there are medical reasons why you shouldn't or can't get pregnant again, you may go through a time of great sadness while you learn to accept the fact of "no more babies." Parents who want another child badly may be bitter and blame God or nature for being so cruel. Parents who consider their family complete just as it is, still often wonder what it would have been like with another child. Even if you eventually would have decided not to get pregnant again anyway, your having the decision taken out of your hands can make it harder to live with. Many people experience some sadness at the end of their childbearing years. When that end has included the death of a baby, it is easy to see why it may take a long time to work through.

If you feel you probably will have another baby, as time

passes you may become more fearful about getting pregnant You ask yourself "How will I get through all those months of waiting?" or "What if something happens again?" If you have no other children or have lost more than one child you may wonder if you ever will have a child to raise If you are older than 35 years, you may feel a sense of urgency about having another child If you had trouble getting pregnant you may be especially anxious about getting started again as soon as possible At the same time, you might feel that getting pregnant again too soon would "dishonor" the memory of your baby Thoughts and feelings like these are all normal One mother described this time of conflict like this "I was in a constant state of agitation about getting pregnant again — wanting it so badly — fearing it so much"

Although there is no advice that will be just right for everyone, there are some things you might consider as you think about another pregnancy

1 Take time for physical recovery from pregnancy A woman's body needs a period of time to prepare for the next pregnancy Your body went through many changes in the months before your baby was born It makes sense to allow enough time for physical recovery and to give your doctor time to treat any condition that may have complicated your pregnancy How long your body needs depends on several things, including the number of previous pregnancies, age type of delivery and your general health Many doctors suggest a minimum of one year for recovery from a pregnancy A well-balanced diet and exercise program (you can get information about these from your Public Health Office) will help you to be in the best possible condition if you do get pregnant again and will give you a feeling you are doing something positive while you wait

2 Take time for emotional healing As you experience

grief and read about what to expect during the months ahead, you begin to realize how long and difficult the experience can be You can remember the many ups and downs of your pregnancy Therefore, you probably can imagine how difficult it is to be pregnant and to mourn at the same time Drs John Kennel and Marshall Klaus are two pediatricians who have had years of experience helping parents whose babies have died In their book "Maternal-Infant Bonding" they offer the following advice

"We strongly encourage parents to refrain from having a replacement infant until they have completed their mourning reaction We explain that it is difficult to take on a new baby at the same time one is giving up the baby who has died These two processes are moving in opposite directions and are extremely difficult to accomplish simultaneously Therefore, we ask parents to wait six months to a year before planning for another baby We encourage them to plan for a new baby in its own right, not to replace the baby who has just died "

Having a new baby while still mourning for the lost baby is very hard on the infant as well as on you.

3. Take time to seek medical advice. It is important to have information about the causes of your baby's death before you get pregnant again It helps to know if what happened was an unusual problem that is unlikely to happen again a physical problem you have or a genetic problem Sometimes a reason cannot be found for what happened, and this can make the idea of another pregnancy more worrisome You may decide to seek special care during your next pregnancy There are doctors and clinics that specialize in caring for women who have had problems in previous pregnancies Your doctor or hospital can give you information about this

Many parents make an appointment with their doctor four to eight weeks after the baby has died to go over the facts of the baby's death While this may seem painful to do having unanswered questions for the rest of your life can be worse Sometimes you have to work hard to find out all the information you need and you might not have very much energy Maybe it just does not seem worth the trouble Perhaps you live far from the hospital where the baby died, or feel uncomfortable asking questions of busy doctors and nurses or are unsure of the questions to ask Sometimes it is hard to understand the medical language We urge you to make that appointment with your doctor anyway, if he has not already made it for you, and keep it if he has! You should ask for explanations you can understand Most people need to hear the explanation more than once before they feel they understand it Having all the facts and knowledge you will need will help a lot as you decide about another pregnancy

4 Take time to make important decisions. One common experience during the mourning period is difficulty in making decisions What seems exactly right today may seem totally wrong tomorrow This is why people who have studied grief advise putting off major decisions until the acute grief period is over This could include things like moving changing jobs, having another baby or deciding not to have any more children Despite hopes that making big changes will ease grief or "take your mind off the death of the baby parents find that the sadness follows them into their new home, their new job, or their next pregnancy Likewise, any decision to use permanent birth control (vasectomy or tubal ligation) should be put off until both parents are absolutely sure they do not want another baby Parents who regret a hasty decision may search desperately for a way to reverse the procedure, and although chances for reversing are improving, you should not count on a successful result

All these suggestions have one thing in common — TIME It has been called the great healer but its progress will seem achingly slow It might help you during this waiting period to think of time as something only you can give to yourself — a gift that will help you to make a wise decision about another pregnancy

BOOKS TO HELP YOU

Now that we have come to the end of our booklet, there are almost certainly things we haven't written about that you would like to know Perhaps it is something about your child's special disease or disability You may be able to find a whole book on the subject at your town's public library, or ask the library staff to send for such a book through interlibrary loan If you live outside town, with no library nearby, you may be able to send for a book through your public school library or from the Wyoming State Library (Supreme Court Building Cheyenne, Wyoming 82002) Most libraries have reference librarians who can help you pick the book which will answer your needs The State Library is open to anyone who lives in the State of Wyoming

We have included a short list of books Reading one or more of them may help you through the difficult months ahead Harriet Sarnoff Schiff's book, "The Bereaved Parent," is highly recommended Even though it is about the death of her 10 year old son, many of the problems she faced you will be facing too She writes with insight and understanding because she and her husband have been through it all She knows what you are going through Your local hospital and your county D-PASS (welfare) Office and Public Health Unit should all have copies which we have sent to them for you to borrow The book is also available for loan from the Improved Pregnancy Outcome Program

LATER

Much later, when you have regained your strength and endurance, when you have lived through your grief and survived, when you can face your baby's life and death with fond memories as well as with remembered pain, there is a special way you can repay the concern, attention and sympathy which was offered to you by family friends and professionals If you feel you have the strength, reach out to some other family whose child has died Show them that if you can endure, so can they if you have survived they will too Not now — it is much too early But perhaps years from now you can reach out and touch someone else's life with concern and reassurance That is how we all survive

BOOKS

The Bereaved Parent, Harriet Sarnoff Schiff, Crown Pubs., 1976

This book offers not only consolation, but practical guidance through the many phases of grief. Available on a loan basis from your local hospital, D-PASS Office, or Public Health Unit.

Living When a Loved One Has Died, Earl A. Grollman, Beacon Press, Boston, 1977

A book about the grieving process and the feelings which accompany it, written in poetic form.

Talking About Death: A Dialogue Between Parent and Child, Earl A. Grollman, Beacon Press, Boston, 1970

A read along picture book explaining death to young children with an extensive guide for parents. Includes lists of pertinent organizations, books, tapes and films.

Helping Your Child to Understand Death, Anna W. Wolf, Child Study Association of America, 50 Madison Avenue, New York, N.Y. 10010. Revised 1973

A booklet which provides sample responses to many questions commonly asked by children.

Talking to Children About Death (Caring About Kids Series). A pamphlet from the U.S. Dept. of Health, Education and Welfare - National Institute of Mental Health, 1979. For a free copy write to: Public Inquiries, National Institute of Mental Health, 5600 Fishers Lane, Rockville, Md. 20857

A brief pamphlet which covers many of the issues involved in talking to children about death and what happens when there is a death in the family.

About Dying — An Open Family Book for Parents and Children Together, Sara Bonnett Stein, Danbury Press, 1974

Clear, honest and sensitive text for children

supplemented by a discussion for adults Ways to assist youngsters with grieving are presented, as well as help in understanding their behavior

Beginnings, Helen Galinsky, Houghton Mifflin, 1976

A young mother's story of two premature births Phillip her first son is born in the days before parents were allowed into premature nurseries and survived after six weeks in the hospital Her second child died soon after birth Contains good descriptions of Phillip's reactions to the death of his brother

Swimmer in the Secret Sea, William Kotzwinkle Avon Books 1975

Moving story of a stillbirth It is the story of a young father and a son-to-be who "briefly swim life's secret sea

FILM

For parents of babies who have died of Sudden Infant Death Syndrome, there is an excellent film called, "You Are Not Alone" available from the Film Library, Division of Health & Medical Services, Hathaway Building, Cheyenne, Wyoming 82002 It is free on a loan basis

NOTES AND QUESTIONS

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